<u>Insight</u>

Alzheimer Society

For people living with dementia

Fall 2022



Creating opportunities in a time of change

As we move into the fall, days become cooler, the sun rises later and nightfall arrives earlier. This time of year, we often think about change. Before you know it, daylight savings time will be upon us and we will have to deal with shifting routines.

Even during the challenge of a transition, there are ways to live a fulfilling life. Take the opportunity to enjoy seasonal activities and think about what you can do differently.

This issue of *Insight*, Myrna Norman, our Leadership Editor, introduces ways researchers and people living with

dementia have collaborated to provide resources, including discussion panels and online forums. We also delve into our support groups and share thoughts from a member of one of our early-stage support groups, which are now available in-person, online and by phone. As well, we share the Alzheimer Society of Canada's latest report on the social and economic impact of dementia, both across Canada and in B.C. Finally, we look at a research study focused on the experiences of people diagnosed with both dementia and cancer.

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Finding balance in nature



Myrna Norman is an advocate who often shares her expertise as someone living with the disease and is a regular contributor to this newsletter. She shares helpful

resources and often moderates panel discussions for other people living with dementia.

Since I last had the opportunity to share my thoughts, wishes and dreams with you, there has been much going on to talk about.

Please sit down while I tell you that although everyone living with dementia is different, we have some vital desires as we travel along our route.

Nature nurtures. We all want to feel the sun, rain and wind on our faces and our bodies. We want to see the storm and smell the air after the storm. We want to feel the softness of the rain kissing our faces or cleansing our hands. We want to feel the winds, feel the power, watch the trees weave and then settle. We want to go to the lake, the beach and the ocean. We want to put our feet in the sand. We want to seek out seashells. We want to smell that fishy air. We want to pick up rocks. We want to see that piece of driftwood, to feel it, to smell it and to see what nature can do.

In a recent panel discussion I participated in, five people living with dementia all reported that being outdoors was not just "a nice feeling," but also necessary to help balance their life. Don't forget where there is a will, there is a way.

Flipping Stigma

Flipping Stigma is an amazing online toolkit designed by an action group, including people living with dementia, caregivers, the general public and health-care providers. Spend some time on the website and if you do not have a computer, perhaps your neighbourhood library or seniors centre can help.

This has educational information and the voices of people with lived experience who address the challenges of stigma and discrimination. It's easy to find, open and learn. For more information visit flippingstigma.com.

Panel discussions

This past summer, I had the privilege of hosting a three-part webinar series, "People living with dementia share their wisdom." All the speakers were people living with dementia. The 90-minute sessions invited people to ask questions and it was helpful to all. For more information and resources, visit the-ria.ca.

Reimagining Dementia

My involvement with Reimagining Dementia has indeed brought me joy. There is a lot of information online and I wish I had a magic wand to make it more accessible to everyone. Find whatever it is that brings you joy. Make a list, send it to me. Birds, babies, bunnies, best friends and so much more. Learn more by visiting reimaginingdementia.com.

Canada Dementia Learning and Resource Network

There are many wonderful insights. Have a look! The website is hub that facilitates collaboration between community-based projects across Canada and is dedicated to supporting the needs of people living with dementia. Learn about resources and upcoming events at cdlrn.the-ria.ca.

September is World Alzheimer's Month. Continue to make it a month of appreciating what you love doing and go outside!

Myrna Norman

"If you are willing to look at another person's behaviour toward you as a reflection of the state of their relationship with themselves rather than a statement about your value as a person, then you will, over a period of time, cease to react at all." – Yogi Bhajan

Get in touch

We welcome contributions from people living with dementia. Please provide your name, mailing address, phone number and/or email address if you would like to be contacted. All submissions will be considered based on theme and space.

Email your ideas or contributions to: insight@alzheimerbc.org

Call 604-681-6530 or toll-free 1-800-667-3742.

Mail to the Alzheimer Society of B.C., Care of *Insight* 300-828 West 8th Avenue Vancouver, B.C. V5Z 1E2

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Finding moments of joy and building connections in support groups

The Alzheimer Society of B.C.'s earlystage support groups are based on the information and mutual aid model, following the philosophy that people in similar situations are in a unique position to give and receive support from others living with early symptoms of dementia.

Living with dementia can be isolating for many, as those in your social network may not be able to fully understand or relate to your experience. A support group provides that connection to others who truly "get it."

Everyone's journey is different, but we see people deeply connect and bond over shared experiences. Sometimes tears and frustrations are shared but often there is laughter and moments of joy shared too. Each group member is much more than their diagnosis and we celebrate life's milestones and accomplishments together. The friendships formed here frequently transcend the group and become a vital lifeline. No one should walk this journey alone; a support group can provide a sense of belonging and camaraderie.

Early-stage support groups and special groups, like Coffee and Chat, are available in-person and online. For more information and to join a group suitable for you, call the First Link® Dementia Helpline at 1-800-936-6033, available Monday to Friday from 9 a.m. to 8 p.m.

Visit page 5 to hear from one of our support group participants about what it's like joining the support groups.



Interview: A sense of belonging and building connections with others on the same journey



Rori is living in the early stages of dementia in Kamloops. Having initiated support groups for immigrants and trained as a facilitator in her earlier years, Rori knew contacting the Society was an opportunity for her to share personal experiences and feelings without being judged. Rori attends the early-stage support group, which is available online, phone and in-person.

Is there anything you look forward to when you are attending your support group?

The social aspects and the sharing of ideas. I feel that we're all equals. It's the support system where we help each other in this difficult situation. I also like our facilitator, who knows how to handle situations, that's very important to me.

What keeps you coming back?

It's real, we're all from different stages. There's a sense of belonging because I know I'm not alone and we understand each other. I can prepare myself because some people are already in later stages of dementia. That way I know, "Oh, that's how it is."

Do you feel like the group offers opportunities for laughter?

Yes, because there's camaraderie and trust being built already. Sometimes we cry, but we're all one. We're all experiencing the same thing, just in a different stage of life.

In what ways have you built a connection with others affected by dementia?

We can agree and disagree without judgement. It's giving encouragement to each other for that person to be successful and overcome whatever challenges they're facing.

Have support groups helped maintain your quality of life?

It helps me to be more social, develop better coping skills and boost my selfesteem. We learn from each other and share how to cope in different situations. There are things I haven't even thought of, but others would have some insight on.

What would you tell others who haven't attended support groups?

Support groups are absolutely essential because they build connections and help create a healthier lifestyle. Whatever you're feeling is validated. It's a safe place where trust has been created and boundaries are respected.

New report highlights impact of dementia

The Alzheimer Society of Canada has just launched the first in a series of three reports known as the Landmark Study, written by Dr. Joshua Armstrong. These reports represent the first significant update on Canada's dementia landscape – along with projections on the future – since the Rising Tide report was released in 2010.

The first report, "Navigating the path forward for dementia in Canada," includes forecasts on the number of people across the country expected to be living with dementia over the next three decades. This forecast includes national breakdowns based on gender and type of dementia. It also looks at the impact on the care partners supporting someone living with the disease, most often their family and friends.

The report offers important insights into the impact of dementia here in B.C. An estimated 85,800 people are living with the disease across the province, while another 50,400 people act as

care partners, providing an estimated 67.9 million hours of unpaid time each year to provide them with support. By 2050, an estimated 247,300 people will be living with dementia in B.C. The impact of this sizable jump cannot be understated, particularly the socioeconomic impact as more people – notably women, given the often gendered nature of caregiving – must step away from their careers to support friends and family living with dementia.

The report outlines steps governments

– as well as individuals – can take to
reduce the risk of developing dementia.
Subsequent volumes of the Landmark
Study will look at the relationship between
ethnocultural background and dementia,
as well as examining the economic impact
of the disease in greater detail.

Learn more

To read the first volume of the Landmark Study, visit alzheimer.ca/landmark-study.



Research opportunity for people diagnosed with cancer and dementia



Dr. Shelley Canning, Associate Professor in Nursing and Director for the Centre for Education and Research on Ageing (CERA) at the University of the Fraser Valley,

has worked as a nurse with people diagnosed with cancer and people living with dementia. Through her working experience, she has witnessed the challenges patients face with the health-care system.

Together with clinicians at BC Cancer, Dr. Canning and her team are

conducting a research study to better understand the experiences of people living with dementia who also have a cancer diagnosis. By examining the experiences and the challenges patients meet, researchers hope to implement a more dementia-friendly community at BC Cancer.

Dr. Canning and her research team are looking to have the help of someone living with both diagnoses to guide the study as a member of their team. Caregivers of the person living with dementia are welcome to participate in the study. If you are interested in learning more, contact Dr. Canning at shelley.canning@ufv.ca or call 604-855-9813.

Dementia around the world: Netherlands

The Netherlands is taking an innovative approach to dementia care by including multi-sensory environments in care centres across the country. These multi-sensory environments are an immersive experience, often equipped with soothing music and large, vibrant visuals. Rather than relying on traditional methods of care such as medication and bed rest, doctors and caregivers are practicing using sensory aids and childhood memories to nurture residents.

A care centre in Amsterdam offers simulated bus rides, with typical bus seats where viewers can sit and enjoy moving images of the Dutch countryside. Another centre in Haarlem has a beach room, replicating a beach environment where residents can sit on lawn chairs grounded in real sand and enjoy heat-regulating lamps, wind and the sound of waves. Not only do these makeshift rooms offer a vacation for people living with dementia, they also attempt to connect to childhood memories and allow residents to share their past experiences with each other. These rooms are aimed to stimulate a positive physiological effect, ultimately reducing levels of stress and discomfort.

For the full article on multi-sensory environments in the Netherlands, visit alzbc.org/Netherlands.

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Contribute

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Call the First Link® Dementia Helpline

A confidential, province-wide support and information service for anyone with questions about dementia. Our English Helpline runs from 9 a.m. until 8 p.m., Monday to Friday. Cantonese or Mandarin and Punjabi Helplines are open from 9 a.m. to 4 p.m., Monday to Friday.

• English: 1-800-936-6033

Punjabi: 1-833-674-5003

Cantonese or Mandarin: 1-833-674-5007

Email supportline@alzheimerbc.org

Are you a caregiver?

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To subscribe:

- Visit our website at alzbc.org/ connections-newsletter
- Call 604-681-6530 or toll-free 1-800-667-3742



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